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Open Neural Tube Defects among Newborns in Rhode Island

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Birth defects, including congenital anomalies and birth injuries, affect approximately 3% of newborns and are the leading cause of infant mortality in the United States.[1] Birth defects are a major cause of morbidity and mortality throughout childhood, and they can have lifelong consequences. Certain birth defects are preventable, and the consequences of others may be minimized through early detection and intervention and the support of a medical home.[2] For example, folic acid has been shown to reduce the risk of neural tube defects.[3]

Programs to reduce poor health outcomes from birth defects require a surveillance system that is able to identify cases and track services provided. In Rhode Island, there has been no data source that provides timely, complete data on birth defects. This report describes a pilot project designed to determine the Rhode Island prevalence of open neural tube defects (ONTDs), including open spina bifida (OSB) and anencephaly, and to assess the outcomes of pregnancies identified with these defects.

Methods. The methodology was based on that used in a similar study in Maine, performed by the Foundation for Blood Research and sponsored by the New England Regional Genetics Group. Data for the period 1991-1997 were obtained from:

1) Vital Statistics: to determine the number of live births and infant deaths with ONTD diagnoses;

2) Women and Infants Hospital (WIH), Division of Prenatal and Special Testing (PST): the number of ONTD pregnancies screened, the number assessed with ONTDs, and the number terminated. PST screens approximately 50% of the state's pregnant women with the maternal serum alpha-fetoprotein (AFP) measure.

3) WIH, Prenatal Diagnostic Center (PDC): to determine additional ONTD pregnancies. PDC provides genetic counseling and follow-up testing (e.g., ultrasonography and amniocentesis).

4) Rhode Island Hospital, Child Development Center (RICDC): to determine any additional ONTD cases, i.e., children not previously identified via other data sources who may have received RICDC services.

These sources identified ONTDs among live-born infants, induced abortions and infant deaths. After cases were identified in each source, the cases were matched to remove duplicates. Because not all databases were statewide, some cases may not have been included. Data are compared with similar data from Maine for 1991-1996.

Results. During the 1991-1997 study period, 97,713 births occurred among Rhode Island residents and 99 pregnancies were identified with ONTDs. Of these 99 ONTDs, 54 were identified with OSB and 45 with anencephaly. Nearly half, 48, of the ONTD pregnancies had been screened, of which 45 (93.7%) were determined positive for an ONTD. (Table 1)

	Type of Open Neural Tube Defect		
	Open Spina Bifida	Anencephaly	Total ONTDs
Total Number of Cases	54	45	99
Number (%) of Cases Screened	30 (55.6%)	18 (44.4%)	48 (48.4%)
Number (%) of Cases Screened Positive	27 (90.0%)	18 (100.0%)	45 (93.7%)
Number (%) of Cases Terminated	22 (40.7%)	40 (88.9%)	62 (62.6%)

Table 1. *Results of Open Neural Tube Defects Screening Study, Rhode Island, 1991-1997*

More than half (59%) of the pregnancies that screened positive for OSB and 100% of those in which anencephaly was identified were terminated. Of the pregnancies that were not screened, 25% of OSB and 81% of anencephaly pregnancies were terminated. Including both screened and unscreened cases, 41% of OSB pregnancies and 89% of anencephaly pregnancies were terminated.

Based on these study data, Rhode Island's prevalence rate of 10.1 ONTD pregnancies per 10,000 pregnancies was slightly lower than Maine's rate of 10.8. (Figure 1) Specifically, the rate of OSB in Rhode Island (5.5 per 10,000) was lower than in Maine (6.4). The rates of anencephaly were nearly the same in Rhode Island and Maine, 4.6 and 4.4, respectively.

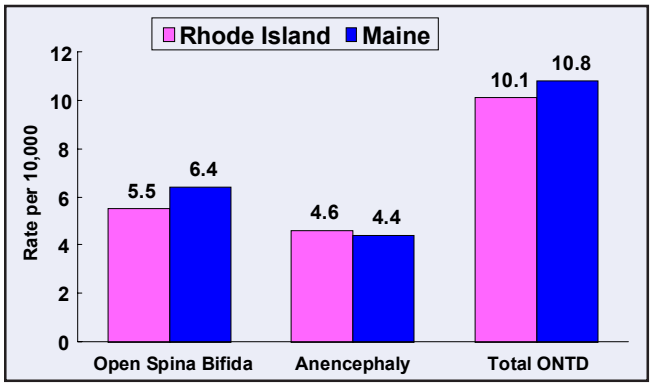

Figure 1. *Incidence of Open Neural Tube Defects per 10,000 Births, by Type of ONTD, Maine (1991-96) and Rhode Island (1991-97).*

Differences were seen in the proportion of pregnancies that were screened. In Rhode Island, 48.4% of the ONTD

pregnancies were screened compared with 60.4% in Maine.

The proportion of ONTD pregnancies that were terminated was virtually the same for both Rhode Island and Maine (63%). Screened cases were more likely to result in terminations. (Figure 2) In Rhode Island, 75.6% of screened positive ONTD pregnancies were terminated compared with 54.9% of ONTD pregnancies that were not screened. The termination rate was higher among anencephaly pregnancies.

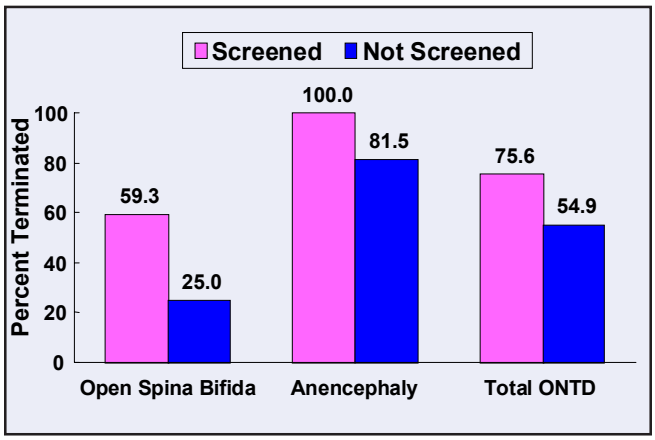

Figure 2. *Termination Rate for Pregnancies with Open Neural Tube Defects, by type of ONTD and Screening Status, Rhode Island, 1991-97.*

The percentage of ONTD pregnancies that were screened was lower in Rhode Island than in Maine. Of the 62 terminations in Rhode Island, 34 (54.8%) had been screened compared with 75.0% in Maine. Rates were similar in both states among OSB terminations, where 72.3% in Rhode Island and 75.9% in Maine had been screened. The percentage of anencephaly terminations that were screened was much lower in Rhode Island (45.0%) than in Maine (74.2%).

Discussion. This study showed the potential benefits from combining data sources for birth defects surveillance. However, the study does have the following limitations:

- Since only 59% of the pregnant women in Rhode Island are screened at WIH, not all screened pregnancies were included. The remainder were screened elsewhere or not screened at all.
- The cause of termination is not captured through Vital Statistics; therefore, termination data were only available for those pregnancies screened at WIH.

A baseline for ONTD occurrence has now been established prior to the introduction of folic acid supplementation. The Rhode Island Department of Health (HEALTH) is working with the Rhode Island Folic Acid Council, the Rhode Island Chapter of the March of Dimes, and other organizations to increase the use of folic acid among women of childbearing age. HEALTH will therefore be able to determine the impact of folic acid supplementation on the incidence of birth defects in Rhode Island.

More resources are now available for birth defects surveillance. HEALTH has received a Centers for Disease Control an Prevention (CDC) grant to design and implement a birth defects surveillance system for all birth defects. This system will be used to identify children with birth defects and track their service utilization. To help ensure access to services, children meeting criteria will be referred for case management and follow-up.

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